October 3, 2022

Director Melanie Fontes Rainer
Department of Health and Human Services
Office of Civil Rights
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

RE: Nondiscrimination in Health Programs and Activities Proposed Rule (RIN 0945-AA17)

Dear Director Fontes Rainer:

On behalf of the American Speech-Language-Hearing Association, I write to offer comments on the Nondiscrimination in Health and Health Programs and Activities proposed rule.

The American Speech-Language-Hearing Association (ASHA) is the national professional, scientific, and credentialing association for 223,000 members and affiliates who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students.

ASHA appreciates the opportunity to comment on several proposed policy changes related to interpreting and enforcing the nondiscrimination provision of the Affordable Care Act (ACA). ASHA supports the work of the Department of Health and Human Services (HHS) to promote and to protect the health care rights of all Americans, and appreciates the reinstatement of 2016 protections.

ASHA's comments focus on several key areas including:

- Designation and Responsibilities of a Section 1557 Coordinator (§ 92.7)
- Notice of Availability of Language Assistance Services and Auxiliary Aids and Services (§ 92.11) and Meaningful Access for Limited English Proficient Individuals (§ 92.201)
- Effective Communication for Individuals with Disabilities (Current § 92.102; Proposed § 92.202) and Accessibility of Information and Communication Technology for Individuals with Disabilities (Current § 92.104; Proposed § 92.204)
- Equal Program Access on the Basis of Sex (§ 92.206)
- Nondiscrimination in the Delivery of Health Programs and Activities through Telehealth Services (§ 92.211)
- Nondiscrimination in Health Insurance Coverage and Other Health-Related Coverage (§ 92.207)
- Enforcement Mechanisms (§ 92.301)

Designation and Responsibilities of a Section 1557 Coordinator

ASHA supports the provision that covered entities must have a designated Section 1557 coordinator. Despite the size of covered entities, it is essential that staff resources are dedicated to coordinating implementation of Section 1557 including developing the required policies and procedures, ensuring employees are trained, receiving and addressing grievances, and informing individuals of their rights when they interact with the covered entity. ASHA acknowledges the potential financial and administrative burden of this provision on smaller practices, but agrees that codified and documented protection from discrimination is in the best interest of patients and providers alike. ASHA appreciates the flexibility that allows covered entities to find an appropriate solution that fits their business model. Solutions could include a part-time coordinator or staff member serving in multiple roles, but ASHA maintains that it is critical for all covered entities to devote designated resources to ensure compliance with the law and these regulations. ASHA further recommends that HHS maximize training and technical assistance to covered entities to reduce the burden of this new requirement.

Notice of Availability of Language Assistance Services and Auxiliary Aids and Services and Meaningful Access for Limited English Proficient Individuals

ASHA supports meaningful access for individuals with limited English proficiency and provisions that ensure that individuals are informed of the availability of these services. In addition, ASHA supports the inclusion of caregivers in language access requirements because a comprehensive patient care team includes caregivers as well as the patient and their providers. Language assistance and auxiliary aids allow providers access to their patients and patient access to their providers.

Research shows that limited proficiency in English is correlated to unmet needs in health care settings While language-concordant care improves patient outcomes over both professional and ad hoc interpreters, it is not always possible depending on the native language of both the available providers and the presenting patient.[1] Professional interpretation, and in exigent circumstances ad hoc interpretation, show demonstrably superior outcomes when compared to no interpretation, regardless of modality.[2]

Translation encompasses more than replacing words from one language to another. Accurate translation is critical for patients. ASHA recommends the stated rule should ensure that individuals who prefer a non-English language and other individuals with disabilities facing structural barriers are guaranteed access to the appropriate communication tools necessary to make effective communication possible in a language and dialect they are fluent in or familiar with.

ASHA agrees that the use of machine translation in health programs and activities should only be acceptable in exigent circumstances. Furthermore, when machine translation is used, the individual should be notified that machine technology was provided in lieu of a human translator due to an exigent circumstance; thus, the translation may not be entirely accurate. Also, the translated printed materials of documents that are critical to the individual's rights should always be reviewed by a qualified human transliterator. This will ensure that accuracy is prioritized. In addition, ASHA maintains that enhanced coordination

with patients will effectively assist HHS in identifying the best ways to communicate patient rights and responsibilities in a manner that meets them where they are.

Effective Communication for Individuals with Disabilities and Accessibility of Information and Communication Technology for Individuals with Disabilities

ASHA supports HHS's proposal to require notice of the availability of auxiliary aids and services for people with disabilities in health programs and activities. People with disabilities have improved access to health services when they are able to access appropriate auxiliary aids and services. A notice that clearly explains the breadth of Section 1557 rights and provides information on how to practically access those protections, including contact information for the entity's 1557 coordinator, is important for people with disabilities.

Access to nondiscriminatory care may be jeopardized when providers lack knowledge of disability-related responsibilities under nondiscrimination laws. Therefore, it is critical that people with disabilities receive notice of their rights to auxiliary aids and services. It is important for covered entities to develop procedures ensuring that people with communication disorders and/or disabilities can understand these notices.

People with disabilities should be notified of their right to request effective communication and auxiliary aids and services, and detailed information about disability function and accommodation needs in electronic health records. Documenting such information in electronic health records would decrease the burden of asking repeatedly for the same accommodations and provide information readily to providers about the needs of the individuals they serve.

While ASHA supports the notice requirements on auxiliary aids and services in § 92.11, ASHA makes the following recommendations to ensure people have meaningful access to communication services:

- Covered entities must ask members/beneficiaries if they have communication disabilities and record their needed auxiliary aid or service in the electronic health record, or paper records as applicable, so that they can consistently receive effective communication from the covered entity.
- Clarify if an individual requests all written communications, relevant to that patient, be rendered in alternative formats or in limited English proficiency languages, then all future communications, including the finite list of significant communications in subsection 92.11(c)(5), should be provided in the requested format or language.
- Develop template notices in plain language formats that will make information accessible to all people regardless of their level of health literacy.

The provision of auxiliary aids and services is a necessary, but insufficient tool for avoiding and remedying effective communication discrimination. This is true regarding the estimated four to five million children, youth, working-aged people, and older adults who cannot rely on natural speech to effectively communicate with others. Instead, such individuals require, but frequently lack, meaningful, effective access to the robust language-based alternative and augmentative communication (AAC) systems they need to express themselves and be understood. A major consequence is that are they are subjected to outdated, unwarranted,

and disproven assumptions and stereotypes that brand them as being less intelligent; being unable to use or even devoid of language; and having less of a human need, ability, or right to effectively communicate. The fact that someone requires robust language-based AAC, can be used to assume they are incapable of "effective communication."

Adequate health insurance coverage for access to AAC is essential to meet medically necessary communication needs. In addition, AAC facilitates the ability of individuals with communication disorders to communicate medical needs with their caregivers, providers, and the public. Adequate coverage of AAC affords individuals greater personal autonomy and the ability to play an active role in their plan of care and crucial life planning decisions.

ASHA applauds HHS's proposed requirement to explicitly require covered entities to provide appropriate auxiliary aids and services to individuals with impaired sensory, manual, or speaking skills, where necessary, to afford them an equal opportunity to benefit from the service in question.

Equal Program Access on the Basis of Sex

ASHA supports the reinstatement of the 2016 definition of sex discrimination to include discrimination on the basis of gender identity and sex stereotyping (45 CFR 92.4). The 2020 rule reversed that interpretation and eliminated the definition of gender identity, which included gender expression and transgender status. While ASHA recognizes that gender identity and gender expression are not explicitly referenced in statute, ASHA maintains that they are covered by the term sex as supported by established case law.[3] ASHA supports transition-related care coverage protections and requirements for the provider to determine the individual's gender.

ASHA's Code of Ethics states that individuals shall not discriminate in the delivery of professional services or in the conduct of research and scholarly activities on the basis of sex, gender identity/gender expression, or sexual orientation. Therefore, ASHA strongly supports the proposed return to 2016 definitions and interpretations against discrimination on the basis of sex to include sexual orientation and gender identity.

ASHA supports coverage protections for transgender individuals and access to gender affirmation services. ASHA members provide vital speech-language pathology services to individuals who want to ensure their voice reflects their gender identity.[4] Currently, , health plans inconsistently cover gender-affirming voice treatment for individuals, even when patients identify it as a key health service related to their transition.[5] According to the 2015 U.S. Transgender Survey, voice treatment is the second most commonly reported medical intervention, behind hair removal, for transgender individuals assigned male at birth.[6] The proposed protections will help ensure improved access to medically necessary voice treatment for transgender individuals.

Nondiscrimination in the Delivery of Health Programs and Activities through Telehealth Services

ASHA supports the explicit addition of telehealth in this proposed rulemaking and maintains that all entities would benefit from a provision addressing accessibility via telehealth given its expanded adoption and utilization during the COVID-19 pandemic. Telehealth is

important for many people with communication disorders and disabilities, but the service only benefits them if it is fully accessible. Including accessibility of telehealth in the Section 1557 nondiscrimination rule helps ensure that health care providers and covered entities do not overlook the needs of individuals with communication disorders and other disabilities and will reduce discrimination against beneficiaries with disabilities resulting from inaccessible telehealth services.

As noted in the proposal, telehealth delivers many benefits such as "lower cost of care and transportation costs, lower exposure to communicable diseases, and access to specialized care including care provided across state lines."[7] Telehealth also provides a wider network of appropriate specialists and enhances availability resulting in shorter wait times for consumers. However, barriers to accessing telehealth can stand in the way of realizing these benefits.

For individuals who are deaf or hard of hearing, telehealth platforms with little to no incorporation of sign language interpretation and/or closed captioning may severely limit access. In addition, the lack of proxy access that would enable care attendants, guardians, and/or support systems to be with disabled patients during tele-visits create a barrier to care coordination and implementation of carryover in the patient's home environment. Also, health care portals and materials that are not in an easy-to-read format and are hard for assistive screen-reading tools to process can cause further challenges for individuals attempting to access telehealth services. Limited access to technology and broadband itself may also threaten access to telehealth services.

While such advancements in telehealth are necessary and promise improved access to care for many individuals, ASHA urges continued development in technology accessibility features described above and cautions against viewing telehealth access as a replacement for in-person visits. Telehealth visits may be beneficial to both patients and providers in multiple ways, but for many people with disabilities, in-person services may still be more accessible, preferred, or clinically necessary for specific individuals and should always remain an option.

Nondiscrimination in Health Insurance Coverage and Other Health-Related Coverage

ASHA strongly supports the prohibition of discrimination in health insurance coverage related to benefit design. Such protections help ensure access to appropriate, medically necessary care for all individuals and are critical for people with communication disorders, other disabilities, and those with serious or chronic conditions.

ASHA opposed the elimination of § 92.207 in past comments and strongly support its proposed reinstatement. ASHA agrees that the rescission of this section ran counter to the intent and purpose of the ACA. For individuals receiving audiology and speech-language pathology services, non-discrimination provisions related to benefit design have been crucial. ASHA also supports the reinstatement of explicit inclusion of protections for transgender individuals related to Section 1557. ASHA also strongly supports the application of Section 1557 to health insurance coverage, especially health benefit designs.

Habilitative and Rehabilitative Services and Devices

Discriminatory benefit design often emerges around habilitative and rehabilitative services and devices. Within this category, people with disabilities and/or chronic conditions experience discrimination based on age, disability, and the type or severity of their disability.

Habilitation and Developmental Disability
Habilitation refers to services or devices that help people gain skills or functioning that they have never had. Rehabilitation refers to services or devices that help people regain skills or functioning that they have lost due to illness or injury. People with developmental disabilities are routinely denied coverage for habilitative services, such as speech therapy, needed to gain skills or improve functioning while an identical service is covered for individuals who require rehabilitative care to restore functioning.

ASHA opposes these blanket service exclusions. Reinstatement of the health-related insurance and other health-related coverage provisions would result in improved coverage of habilitation for people with developmental disabilities and address what ASHA views as prohibited discrimination on the basis of disability (28 CFR 35 and 42 USC 18022(b)(4)(B)).

Hearing Aids
Health plans often apply age limits on coverage for hearing aids. Several essential health benefit (EHB) benchmark plans offer no coverage at all or limit coverage to children only. Failure to cover hearing aids discriminates against a specific segment of people with hearing loss. In addition, coverage of hearing aids for children only and not for adults potentially violates the ACA prohibition against discrimination in plan design based on age.

ASHA supports HHS's proposal to reinstate regulations that prohibit discrimination on the basis of association with a protected class (45 CFR 92.209). Courts have upheld such a right for exactly the types of patients that ASHA members treat.[8] Prohibition against discrimination based on an individual's association or relationship will clarify the responsibilities of providers and the rights of persons who experience discrimination. In addition, this provision would bring the ACA Section 1557 in line with other regulatory requirements including the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

Enforcement Mechanisms

ASHA supports the reinstatement of § 92.301 and appreciates the clear language in the preamble confirming that enforcement mechanisms include a private right of action. ASHA maintains that, in the interest of transparency and patient protection, it is helpful to include language about the private right of action in the rule.

OCR seeks comment on the extent, scope, and nature of value assessment methods that discriminate on the basis of race, color, national origin, sex, age, or disability. Current alternative payment models take limited account of a person's functional status or socioeconomic characteristics, even though these can be strong predictors of health spending and need.[9] This may adversely incentivize providers to "cherry pick" their patients to ensure the best possible outcomes on quality measures. ASHA maintains that accurate

risk adjustment, which considers functional status and social factors, could offset the unintended consequence of dis-incentivizing care for underserved populations that exacerbates health inequity in pursuit of quality incentives. Monitoring of demographic and social risk data would help ensure efforts to increase health equity are working as intended.

In closing, ASHA supports the proposed changes reinstating essential protections to prevent and remedy discrimination against all patients, including those served by audiologists and speech-language pathologists. In addition, ASHA appreciates the opportunity to provide comments on this proposed rule and looks forward to working with you to implement these provisions. If you or your staff have any questions, please contact Rebecca Bowen, ASHA's Director of Health Care Policy, Value and Innovation, at rbowen@asha.org

Sincerely,

Judy Rich, EdD, CCC-SLP, BCS-CL
2022 ASHA President

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[2] Boylen S., Cherian, S., Gill, F.J., Leslie, G.D., Wilson, S. Impact of professional interpreters on outcomes for hospitalized children from migrant and refugee families with limited English proficiency: a systematic review. JBI Evid Synth. 2020 Jul;18(7):1360-1388. doi: 10.11124/JBISRIR-D-19-00300. PMID: 32813387.
[3] *Bostock v. Clayton County, Georgia*
[4] American Speech-Language-Hearing Association. (n.d.). *Voice and Communication Services for Transgender and Gender Diverse Populations.* https://www.asha.org/practice-portal/professional-issues/transgender-gender-diverse-voice-and-communication/.
[5] Babajanians, T. (1 Feb 2019). Giving Voice to Gender Expression. The ASHA Leader. https://leader.pubs.asha.org/doi/10.1044/leader.FTR2.24022019.54.
[6] National Center for Transgender Equality. (2015). U.S. Transgender Survey. http://www.transequality.org/sites/default/files/docs/usts/USTS%20Full%20Report%20-%20FINAL%201.6.17.pdf.
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[8] Falls v. Prince George's Hosp. Ctr., No. Civ. A 97–1545, 1999 WL 33485550 at * 11 (D. Md. Mar. 16, 1999) (holding that parent had an associational discrimination claim under Section 504 when hospital required hearing parent to act as interpreter for child who was deaf). Cf. Questions and Answers About the Americans with Disabilities Act's Association Provision.
[9] Zhu, Michael, et al. (29 June 2022). The Future of Risk Adjustment: Supporting Equitable, Comprehensive Health Care [Issue Brief] Duke Margolis Center for Health Policy.